

# Dichiarazione: *assenza di conflitti di interesse*

 **fondazione GIMEMA** onlus  
per la promozione e lo sviluppo della ricerca scientifica  
sulle malattie ematologiche. **FRANCO MANDELLI**

Si ringrazia per il supporto



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Con il patrocinio di

LE CURE PALLIATIVE PRECOCI IN  
**EMATO-ONCOLOGIA:**  
la nuova risposta ai bisogni di pazienti e caregivers

**19 maggio 2023**

**Roma, Hotel Donna Camilla Savelli**



# Le Cure Palliative Precoci in Onco-Ematologia ed i Caregivers: quali Evidenze

*Elena Bandieri, MD - AUSL Modena, Italy*

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# ONCOLOGY CAREGIVERS: EPIDEMIOLOGY

USA	ITALY
40 ML	3 ML



## ONCOLOGY CAREGIVERS : CHARACTERISTICS

<b>FEMALE</b>	<b>&gt; 70%</b>
<b>LOWER AVERAGE AGE</b>	<b>50-56 YEARS</b>
<b>MORE INTENSIVE CARE</b>	<b>&gt; 17 HOURS WEEK</b>
<b>YOUNGER PATIENTS</b>	<b>55-70 YEARS</b>



# ONCOLOGY CAREGIVERS :

## ADVERSE MENTAL HEALTH OUTCOME

CAREGIVERS	PATIENTS
40%-42%	27%-28 %



# Early Palliative Care Tasks

**EPC tasks**, include comprehensive assessment and management of physical symptoms and psychological distress and the prognostic awareness of patients, support in decision making-treatment choices-future planning, facilitation of coping with life-threatening disease and **providing physical and psychosocial, spiritual and emotional support both to patients and primary caregivers, also after bereavement.**



# Which Evidence?

- **Randomized Controlled Trials**
- Qualitative/Quantitative Studies in the Real Life Setting
- Stigma about Palliative Care



# Palliative Care for Family Caregivers

Sorayya Alam, MBChB<sup>1,2</sup>; Breffni Hannon, MBChB, MSc<sup>1,2</sup>; and Camilla Zimmermann, MD, PhD<sup>1,2</sup>

TABLE 3. Randomized Controlled Trials Assessing Outcomes for Caregivers of Patients With Advanced Cancer

First Author	Setting	Population	Intervention	Quality of Life	Mental Health	Caregiving	Other
Interventions directed at the caregiver alone							
Holm <sup>59</sup>	Community palliative care, Sweden	270 CGs, advanced cancer	Three manualized multidisciplinary group sessions	NS (nonspecific measure)	NS (depression, anxiety)	MF <sup>a</sup>	
Fegg <sup>60</sup>	Inpatient palliative care, radiation, Germany	160 CGs, 81% advanced cancer, 19% noncancer	Six existential behavioral therapy group sessions	MF (nonspecific measures) <sup>b</sup>	MF (depression, anxiety) <sup>b</sup>	NM	NS (somatization)
Hudson <sup>61,62</sup>	Community palliative care, Australia	298 CGs, advanced cancer	Nursing assessment of needs, guidebook, care planning	NM	NS (distress) <sup>f</sup>	MF <sup>c</sup>	MF (bereavement distress) <sup>f</sup>
Walsh <sup>63</sup>	Community palliative care, United Kingdom	271 CGs, advanced cancer	Nurses and social workers providing advice and support	NS (nonspecific and specific)	NS (distress)	NS (strain)	NS (satisfaction, grief)
McMillan <sup>64</sup>	Community-based hospice, United States	329 CGs, advanced cancer	Three nursing visits to teach coping skills	FI (CG-specific measure)	NM	MF <sup>d</sup>	
Hudson <sup>65</sup>	Community palliative care, Australia	106 CGs, advanced cancer	Two nursing home visits, phone call, guidebook, audiotapes	NM	NS (anxiety)	NS <sup>e</sup>	
Interventions directed at patient-caregiver dyads							
DuBenske <sup>66</sup>	Four cancer centers, United States	285 dyads, advanced lung cancer	Online information, communication, and coaching	NM	FI (mood)	MF <sup>f</sup>	
Northouse <sup>67</sup>	Four cancer centers, United States	484 dyads, advanced cancer	Nursing home visits and phone sessions	MF (nonspecific measure) <sup>g</sup>	NM	MF <sup>g</sup>	
Northouse <sup>68</sup>	Three cancer centers, United States	263 dyads, prostate cancer	Three nursing home visits and two phone sessions	FI (nonspecific measure) <sup>h</sup>	FI (mental health, 4 months) <sup>h</sup>	MF <sup>h</sup>	
Northouse <sup>69</sup>	Four cancer centers, United States	182 dyads, recurrent breast cancer	Nursing home visits and phone sessions	NS (CG-specific measure)	NS (mental health)	MF <sup>i</sup>	NS (uncertainty, hopelessness)

Review of **RCTs published since 2005**, reporting on quality of life, mental health, and caregiving outcomes for caregivers of patients with advanced cancer





# Palliative Care for Family Caregivers

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Interventions directed at the patient and their family						
El-Jawahri <sup>70</sup>	Outpatient clinics, cancer center, United States	275 CGs, advanced noncolorectal GI or lung cancer	Early PC addressing needs of patients and caregivers	NS (nonspecific measure)	FI (distress, depression at 12 weeks)	NM

(continued on following page)

TABLE 3. Randomized Controlled Trials Assessing Outcomes for Caregivers of Patients With Advanced Cancer (continued)

First Author	Setting	Population	Intervention	Quality of Life	Mental Health	Caregiving	Other
McDonald <sup>71</sup>	Outpatient clinics, cancer center, Canada	182 CGs, advanced cancer	Early PC addressing needs of patients and caregivers	NS (nonspecific and specific)	NM	NM	FI (satisfaction with care)
El-Jawahri <sup>72</sup>	Inpatient tertiary care hospital, United States	94 CGs, inpatients receiving HCT	Early PC with focus on managing patient's symptoms	MF (CG-specific measure) <sup>a</sup>	MF (depression, anxiety) <sup>k</sup>	NM	FI (coping)
Dionne-Odom <sup>73</sup>	Approximately 50% rural, 50% urban, United States	122 CGs, advanced cancer	Early PC, including telephone coaching sessions with advanced practice nurse <sup>l</sup>	NS (CG-specific measure)	FI (depression)	MF <sup>m</sup>	NS (post-bereavement depression, grief)
O'Hara <sup>74</sup>	Approximately 50% rural, 50% urban, United States	198 CGs, advanced cancer	Patient-focused early PC; nurse-led phone education sessions	NM	NM	NS (burden)	
Clark <sup>75</sup>	Radiation therapy clinic, United States	83 CGs, cancer, palliative radiation	Eight-session multidisciplinary intervention (patients)	NS (nonspecific measure)	NM	NS (burden)	

There were **mixed results** across studies and interventions.

The most consistently **favorable results were for depression, particularly for caregivers participating in early palliative care interventions.**



**Positive results for depression** in a trial of **early** versus delayed palliative care, where **caregivers** of patients in the intervention group received six and three additional structured weekly telephone coaching sessions, monthly follow-up, and a bereavement call.

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ORIGINAL REPORT

Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial

*J. Nicholas Dionne-Odom, Andres Azuero, Kathleen D. Lyons, Jay G. Hull, Tor Tosteson, Zhigang Li, Zhongze Li, Jennifer Frost, Konstantin H. Dragnev, Imatullah Akyar, Mark T. Hegel, and Marie A. Bakitas*

**Early-group:** Caregivers had lower depression (6% decrease) and stress burden in the terminal decline analysis.

**Palliative care for Care Givers should be initiated as early as possible** to maximize benefits.



**Effects of Early Integrated Palliative Care on Caregivers of Patients with Lung and Gastrointestinal Cancer: A Randomized Clinical Trial**

AREEJ EL-JAWAHRI,<sup>a,b</sup> JOSEPH A. GREER,<sup>a,b</sup> WILLIAM F. PIRL,<sup>a,b</sup> ELYSE R. PARK,<sup>a,b</sup> VICKI A. JACKSON,<sup>a,b</sup> ANTHONY L. BACK,<sup>c</sup> MIHIR KAMDAR,<sup>a,b</sup> JULIET JACOBSEN,<sup>a,b</sup> EVA H. CHITTENDEN,<sup>a,b</sup> SIMONE P. RINALDI,<sup>a</sup> EMILY R. GALLAGHER,<sup>a</sup> JUSTIN R. EUSEBIO,<sup>a</sup> SARAH FISHMAN,<sup>a,b</sup> HARRY VANDUSEN,<sup>a,b</sup> ZHIGANG LI,<sup>d</sup> ALONA MUZIKANSKY,<sup>a,b</sup> JENNIFER S. TEMEL<sup>a,b</sup>

**Results for caregivers' depression also favored the intervention group** in a trial of EPC for patients with **advanced lung or GI cancers**

**Table 3.** Effect of early integrated palliative care on caregivers' outcomes at 3 and 6 months prior to death

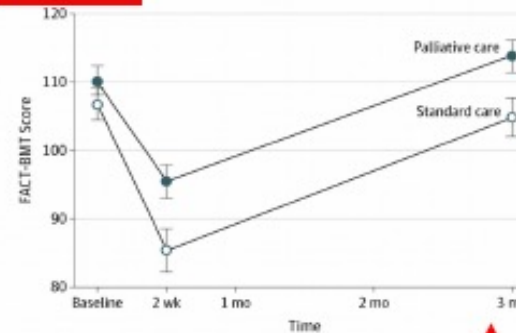
Entire sample <sup>a</sup>	3 months before death			6 months before death		
	Mean	(95% CI)	<i>p</i> value	Mean	(95% CI)	<i>p</i> value
HADS-Total distress			<b>.002</b>			<b>.003</b>
Early palliative care	6.84	(4.11–9.58)		7.88	(6.16–9.61)	
Usual care	12.93	(10.28–15.59)		11.60	(9.89–13.31)	
SF-36 PCS			.664			.299
Early palliative care	52.69	(51.00–54.38)		53.27	(51.71–54.83)	
Usual care	52.17	50.56–53.57		52.14	(50.67–53.61)	
SF-36 MCS			.579			.338
Early palliative care	46.75	(44.88–48.62)		47.10	(45.33–48.87)	
Usual care	46.01	(44.23–47.80)		45.91	(44.25–47.57)	



160 HSCT patients randomized to receive EPC vs standard care.

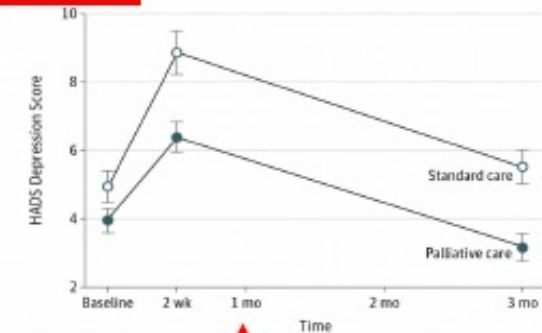
In-patient EPC by either a physician or a nurse twice a week, until discharge

**A Patient quality of life**



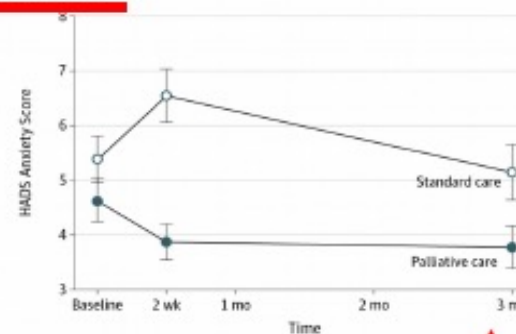
No. of patients	81	80	75
Palliative care	81	80	75
Standard care	79	77	74

**B Patient depression**



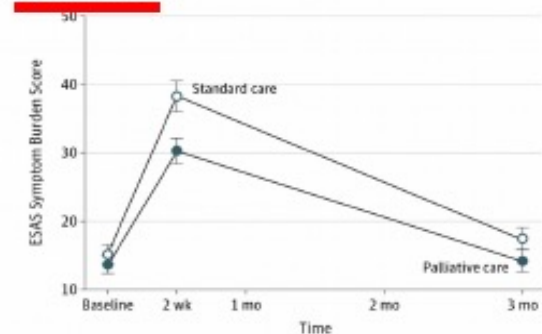
No. of patients	81	80	74
Palliative care	81	80	74
Standard care	79	77	74

**C Patient anxiety**



No. of patients	81	80	74
Palliative care	81	80	74
Standard care	79	77	74

**D Patient symptom burden**



No. of patients	77	75	69
Palliative care	77	75	69
Standard care	79	77	71

**El Jawahri AR et al. JAMA. 2016;316(20):2094-2103.**



Results for caregivers' depression also **avored the intervention group for one of two measures of depression** in a trial of early inpatient palliative care for patients undergoing hematopoietic stem-cell transplantation.

Week-2 outcomes (N = 94)	Adjusted Beta†	95% Confidence Interval	P- Value
FC-QOL	3.66	-1.28 to 8.61	0.146
Psych	0.60	-0.62 to 1.82	0.334
Burden	0.68	-0.41 to 1.77	0.219
Relationship health care	-0.25	-1.08 to 0.57	0.552
Administrative and finances	0.72	0.10 to 1.35	<b>0.024</b>
Coping	0.97	0.15 to 1.79	<b>0.021</b>
Physical	0.50	-0.56 to 1.56	0.357
Self-esteem	<b>-0.18</b>	<b>-0.71 to 0.34</b>	0.494
Leisure	0.25	-0.38 to 0.89	0.438
Private Life	0.64	-0.09 to 1.37	0.086
Social support	-0.25	-0.83 to 0.34	0.405
FC depression	-1.79	-3.39 to -0.18	<b>0.029</b>
FC anxiety	-0.07	-1.54 to 1.41	0.926
FC PHQ	-0.29	-1.90 to 1.32	0.725



# Palliative Care for Family Caregivers

Sorayya Alam, MBChB<sup>1,2</sup>; Breffni Hannon, MBChB, MSc<sup>1,2</sup>; and Camilla Zimmermann, MD, PhD<sup>1,2</sup>

Trials of palliative care interventions tended to focus on patient outcomes and to be underpowered to detect effects for caregivers, especially for bereavement outcomes.

This area of research is still in an early stage of development, and more work needs to be done before there are interventions that are ready for widespread dissemination and implementation.



- Randomized Controlled Trials
- **Qualitative/Quantitative Studies: Real Life Setting**
- Stigma about Palliative Care



**TABLE 4.** The CARES Framework for Family Caregivers

Domain	Description
Consider caregivers as part of the unit of care	Consider caregivers as part of the unit of care as well as part of the care team
	Acknowledge the importance of the caregiving role
	Respect the patient's wishes regarding the nature and degree of caregiver participation in decision making
Assess the caregiver's situation, perceptions, and needs	Document the caregiver's relationship to the patient, their living situation, employment, and whether care is being provided for other dependents (eg, children)
	Assess the caregiver's capacity and willingness to provide care
	Inquire about the caregiver's physical and mental health
	Assess the impact of caregiving, including social isolation and financial strain
	Inquire about the caregiver's perception of the patient's status and ability for self-care
Refer to appropriate services and resources	Refer the caregiver to locally available resources:
	Palliative care teams, hospice,
	Home care services, respite care
	Social work, psychology, spiritual care
Educate about practical aspects of caregiving	Community resources, support groups, online resources
	Ensure the caregiver and patient have a joint understanding of the patient's cancer, its treatment, its typical course, and signs of advancing disease
	Check understanding of pain control (eg, dosing, adverse effects, addiction potential)
	Ensure education for practical skills (eg, dressing changes, injections, lifting/transferring)
Support caregivers through bereavement	Highlight the importance of personal health and self-care and the availability of benefits and services for caregivers
	Clarify when it is important to call and who should be called
	Be available by phone or in person to discuss caregiver concerns
	Offer referral to local bereavement support services
	Call or send a card to the caregiver after bereavement

A framework **to address the needs of family caregivers** has been developed at the Oncology Palliative Care Clinic, at the Princess Margaret Cancer Centre, Toronto.

Similar framework at the **OUTPATIENT EPC Ambulatory** in AUSL Modena





# COMMUNICATION IN EPC

Highly interdisciplinary research at the confluence of medical, language and cognitive sciences, aimed at encouraging and improving the evolution of communication, studying the affective meaning and semantics of words associated with suffering and hope in oncology and hematology patients.

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RESEARCH ARTICLE

Different semantic and affective meaning of the words associated to physical and social pain in cancer patients on early palliative/supportive care and in healthy, pain-free individuals

Eleonora Borelli<sup>1,2\*</sup>, Sarah Bigi<sup>3</sup>, Leonardo Potenza<sup>4,5</sup>, Fabrizio Artioli<sup>6</sup>, Sonia Eliardo<sup>6</sup>, Claudia Mucciarini<sup>6</sup>, Katia Cagossi<sup>6</sup>, Giorgia Razzini<sup>6</sup>, Antonella Pasqualini<sup>6</sup>, Fausta Lui<sup>1,2</sup>, Fabio Ferlazzo<sup>7</sup>, Massimiliano Cruciani<sup>8</sup>, Eduardo Bruera<sup>9</sup>, Fabio Efficace<sup>9</sup>, Mario Luppi<sup>4,5,e</sup>, Cristina Cacciari<sup>1,2,e</sup>, Carlo Adolfo Porro<sup>1,2,e</sup>, Elena Bandieri<sup>6,e</sup>

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## Perceptions of Hope Among Bereaved Caregivers of Cancer Patients Who Received Early Palliative Care: A Content and Lexicographic Analysis

Sarah Bigi<sup>1,\*</sup>, Vittorio Ganfi<sup>2</sup>, Eleonora Borelli<sup>2</sup>, Leonardo Potenza<sup>2,3</sup>, Fabrizio Artioli<sup>4</sup>, Sonia Eliardo<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Cristina Cacciari<sup>5,6</sup>, Oreofe Odejide<sup>7,†</sup>, Carlo Adolfo Porro<sup>5,6,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Efficace<sup>10,†</sup>, Eduardo Bruera<sup>11,†</sup>, Mario Luppi<sup>2,3,\*</sup>, Elena Bandieri<sup>4,†</sup>

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Mindfulness-Based stress reduction in early palliative care for people with metastatic cancer: A mixed-method study

Stefano Poletti<sup>1,\*,1</sup>, Giorgia Razzini<sup>1,1</sup>, Roberto Ferrari<sup>1,1</sup>, Maria Pia Ricchieri<sup>1</sup>, Giorgio Alfredo Spedicato<sup>6</sup>, Antonella Pasqualini<sup>6</sup>, Cristina Buzzega<sup>6</sup>, Fabrizio Artioli<sup>6</sup>, Kyriakoula Petropulacos<sup>8</sup>, Mario Luppi<sup>6</sup>, Elena Bandieri<sup>6</sup>

The Oncologist®

Symptom Management and Supportive Care

## Changes in cancer patients' and caregivers' disease perceptions while receiving early palliative care: a qualitative and quantitative analysis

Eleonora Borelli<sup>1</sup>, Sarah Bigi<sup>2</sup>, Leonardo Potenza<sup>3,4</sup>, Sonia Eliardo<sup>4</sup>, Fabrizio Artioli<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Katia Cagossi<sup>4</sup>, Giorgia Razzini<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Alessandra Pietramaggiore<sup>4</sup>, Valeria Fantuzzi<sup>4</sup>, Laura Lombardo<sup>4</sup>, Umberto Ferrari<sup>4</sup>, Vittorio Ganfi<sup>4</sup>, Fausta Lui<sup>4,5</sup>, Oreofe Odejide<sup>6</sup>, Cristina Cacciari<sup>4,7</sup>, Carlo Adolfo Porro<sup>4,7,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Efficace<sup>10,†</sup>, Eduardo Bruera<sup>11,†</sup>, Mario Luppi<sup>4,8,†</sup>, Elena Bandieri<sup>4,†</sup>

## Perceptions of Death Among Patients with Advanced Cancer Receiving Early Palliative Care and Their Caregivers: Results from a Mixed-Method Analysis

Sarah Bigi<sup>1,\*</sup>, Vittorio Ganfi<sup>2</sup>, Eleonora Borelli<sup>2,†</sup>, Leonardo Potenza<sup>2,3</sup>, Fabrizio Artioli<sup>4</sup>, Sonia Eliardo<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Umberto Ferrari<sup>4</sup>, Laura Lombardo<sup>4</sup>, Katia Cagossi<sup>4</sup>, Alessandra Pietramaggiore<sup>4</sup>, Valeria Fantuzzi<sup>4</sup>, Iliaria Bernardini<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Cristina Cacciari<sup>5,6</sup>, Oreofe Odejide<sup>7,†</sup>, Carlo Adolfo Porro<sup>5,6,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Efficace<sup>10,†</sup>, Eduardo Bruera<sup>11,†</sup>, Mario Luppi<sup>1,2,3,†</sup>, Elena Bandieri<sup>4,†</sup>

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Gratitude among advanced cancer patients and their caregivers: The role of early palliative care

Eleonora Borelli<sup>1,†</sup>, Sarah Bigi<sup>2</sup>, Leonardo Potenza<sup>1,3</sup>, Fabio Gilioli<sup>4</sup>, Fabrizio Artioli<sup>5</sup>, Giampiero Porzio<sup>6,†</sup>, Carlo Adolfo Porro<sup>7,8,†</sup>, Fabio Efficace<sup>9,†</sup>, Eduardo Bruera<sup>10,†</sup>, Mario Luppi<sup>1,3,†</sup> and Elena Bandieri<sup>5,†</sup>



## Changes in cancer patients' and caregivers' disease perceptions while receiving early palliative care: a qualitative and quantitative analysis

ELEONORA BORELLI <sup>1</sup>, SARAH BIGI <sup>2</sup>, LEONARDO POTENZA <sup>1,3</sup>, SONIA EUJARDO <sup>4</sup>, FABRIZIO ARTIOLI <sup>1</sup>, CLAUDIA MUCCIARINI <sup>4</sup>, LUCA COTTAFANI <sup>4</sup>, KATIA CAGOSSI <sup>4</sup>, GIORGIA RAZZINI <sup>1</sup>, MASSIMILIANO CRUCIANI <sup>4</sup>, ALESSANDRA PIETRAMAGGIORI <sup>4</sup>, VALERIA FANTUZZI <sup>4</sup>, LAURA LOMBARDO <sup>4</sup>, UMBERTO FERRARI <sup>4</sup>, VITTORIO GANFI <sup>1</sup>, FAUSTA LUI <sup>5,6</sup>, OREOFE ODEJIDE <sup>1</sup>, CRISTINA CACCIARI <sup>5,6</sup>, CARLO ADOLFO PORRO <sup>5,6,7</sup>, CAMILLA ZIMMERMANN <sup>1,8,9</sup>, FABIO EFFICACE <sup>1,10</sup>, EDUARDO BRUERA <sup>1,11</sup>, MARIO LUPPI <sup>1,3,12</sup>, ELENA BANDIERI <sup>4,13</sup>

*The Oncologist* 2021;9999:• • [www.TheOncologist.com](http://www.TheOncologist.com)

- 77 patients with advanced cancer and 48 caregivers; semistructured interviews. Qualitatively and quantitative analysis by the grounded theory and a text-analysis program
- Once the problem of physical pain has been resolved, the role of doctor-patient-caregiver communication in the management of suffering comes into play.
- The resolution of pain/suffering generates an increase in cognitive and emotional resources which allows one to face the disease, improve the alliance with the doctor, up to the ability to acquire a more serene and open attitude towards death.



## Table 2. Emerging themes and illustrative quotations referred to the past

Psychological impact on caregivers:	“While seeing my husband deteriorating and suffering, I was very depressed, I felt alone and helpless [seeing the beloved’s suffering], because I was trying to face something greater than me.” (002-C-037)
<ul style="list-style-type: none"> <li>• Seeing the beloved’s suffering</li> <li>• Being thrown into the role</li> </ul>	“I found myself catapulted into a world that was unknown to me [being thrown into the role]; I have never had the dramatic experience of beloveds becoming ill, with rather hard and critical diagnoses, so I was almost unaware of everything that the disease entails and the way a caregiver could approach this path [being thrown into the role].” (002-C-019)

## Table 3. Emerging themes and illustrative quotations referred to the present



- Caregivers more focused on the end of life	“Early palliative care is the only way to accompany the patient and his family in a relation of truth and awareness, helping to approach the idea of death and death itself, without anguish and denial; my wife was released from pain and I had the chance to prepare myself to say good bye to my beloved, to say and to do the things, I considered and felt more focused on the end of life.” (002-C-035)
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## Table 4. Emerging themes and illustrative quotations referred to the future

Caregivers:	“To see my sister peaceful is everything to me [acceptance tied to the beloved’s acceptance, absence of suffering].” (002-C-041)
<ul style="list-style-type: none"> <li>• Acceptance tied to the beloved’s acceptance</li> <li>• Not left alone</li> </ul>	<p>“A thing that I have realized is that death is not acceptable if it is accompanied by great suffering. Before these treatments, my husband’s illness was just huge suffering [acceptance tied to the beloved’s acceptance, absence of suffering].” (002-C-014)</p> <p>“To me (...) it is important that his life is a decent and pain-free life [acceptance tied to the beloved’s acceptance, absence of suffering].” (002-C-035)</p> <p>“I feel taken by the hand [caregiver not left alone], I don’t feel lonely and desperate like I was before coming here.” (002-C-040)</p>



# Perceptions of Hope Among Bereaved Caregivers of Cancer Patients Who Received Early Palliative Care: A Content and Lexicographic Analysis

Sarah Bigi<sup>1,\*</sup>,, Vittorio Ganfi<sup>2</sup>, Eleonora Borelli<sup>2</sup>, Leonardo Potenza<sup>2,3</sup>, Fabrizio Artioli<sup>4</sup>, Sonia Eliardo<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Cristina Cacciarini<sup>5,6</sup>, Oreofe Odejide<sup>7,†</sup>, Carlo Adolfo Porro<sup>5,6,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Efficace<sup>10,†</sup>,, Eduardo Bruera<sup>11,†</sup>, Mario Luppi<sup>2,3,\*</sup>,†, Elena Bandieri<sup>4,†</sup>

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**Original Article**

- 36 primary caregivers of patients who received EPC
- Caregivers perceived hope mainly as resilience EPC interventions were recalled as the major support for hope, both during the illness and after the death of the patient
- By telling the truth about an incurable disease and beginning EPC might be the combination of factors triggering hope in the setting of incurable cancer



**Table 3.** Descriptions of hope as resilience.

Hope as resilience	
0-C-008	“Hope is truth...It is finding the strength to stand by each other even in the hardest of times”
Hope as expectation	
01-C-003	“It is the absence of suffering, of desperation, of illusion”
0-C-008	“Standing by each other so that memories will be full of emotions, feelings, discussions and words that will accompany you for the rest of your life”
0-C-010	“The highest spiritual dimension that reminds us that we will live forever, that death is only a transition”
01-C-028	“It is the absence of suffering and desperation”
01-C-025	“Hope of feeling well as long as possible and live fully the time that is left”
01-C-032	“Hope is to die peacefully”

**Table 5.** Descriptions of inspiring relationships as antecedents of hope.

Inspiring relationships as antecedents of hope	
01-C-018	“A small party that my partner organized for her doctors and nurses and a few friends met along the way at the clinic; I remember that time of happiness, smiles, sharing and I thought that everything was perfect and that what scared me so much was something I could face after all”
01-C-022	“The feeling of complete trust my father had in the healthcare team”
01-C-026	“The way he smiled when he knew he had to go to the clinic or when he talked with the doctor or other members of the team on the telephone; he said that just hearing their voices made him feel better”

0-C-008

“Hope is truth...It is finding the strength to stand by each other even in the hardest of times”

to be very troubled he in the healthcare team; critical moments”  
first encounter with the bed and left, I can't ex-

plain, but we were smiling”

## Perceptions of Death Among Patients with Advanced Cancer Receiving Early Palliative Care and Their Caregivers: Results from a Mixed-Method Analysis

Sarah Bigi<sup>\*1</sup>, Vittorio Ganfi<sup>2</sup>, Eleonora Borelli<sup>2,†</sup>, Leonardo Potenza<sup>2,3</sup>, Fabrizio Artioli<sup>4</sup>, Sonia Eliardo<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Umberto Ferrari<sup>4</sup>, Laura Lombardo<sup>4</sup>, Katia Cagossi<sup>4</sup>, Alessandra Pietramaggiori<sup>4</sup>, Valeria Fantuzzi<sup>4</sup>, Ilaria Bernardini<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Cristina Cacciarini<sup>5,6</sup>, Oreofe Odejide<sup>7,†</sup>, Carlo Adolfo Porro<sup>5,6,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Efficace<sup>10,†</sup>, Eduardo Bruera<sup>11,†</sup>, Mario Luppi<sup>\*2,3,†</sup>, Elena Bandieri<sup>4,†</sup>

*The Oncologist*, 2023, 28, e54–e62  
<https://doi.org/10.1093/oncolo/oyac227>

- Qualitative and quantitative analyses were performed on 2 databases: (a) transcripts of open-ended questionnaires administered to 115 primary caregivers of patients on EPC; (b) texts collected from an Italian forum, containing instances of web-mediated interactions between patients and their caregivers
- patients and caregivers are not afraid of speaking about death
- patients and caregivers on EPC use the word “death” significantly more than patients and their caregivers on standard oncology care
- EPC interventions, along with proper physician-patient communication, may be associated with an increased acceptance of death



# Gratitude among advanced cancer patients and their caregivers: The role of early palliative care

Eleonora Borelli<sup>1\*</sup>, Sarah Bigi<sup>2</sup>, Leonardo Potenza<sup>1,3</sup>,  
Fabio Gilioli<sup>4</sup>, Fabrizio Artioli<sup>5</sup>, Giampiero Porzio<sup>6†</sup>,  
Carlo Adolfo Porro<sup>7,8†</sup>, Fabio Efficace<sup>9†</sup>, Eduardo Bruera<sup>10†</sup>,  
Mario Luppi<sup>1,3\*†</sup> and Elena Bandieri<sup>5†</sup>



TYPE Original Research  
PUBLISHED 24 October 2022  
DOI 10.3389/fonc.2022.991250

- Reports from **118 caregivers of patients under EPC**. Words expressing gratitude and words referring to communication and spirituality were collected by means of the Linguistic Inquiry and Word Count software and correlated
- **(92.2%)** of caregivers' reports **included explicit or implicit expressions of gratitude**
- Gratitude was **associated with successful physical symptom management (pain), emotional support, improved attitude toward death, better communication.**



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Carlo Adolfo Porro<sup>7,8†</sup>, Fabio Efficace<sup>9†</sup>, Eduardo Bruera<sup>10†</sup>,  
Mario Luppi<sup>1,3\*†</sup> and Elena Bandieri<sup>5†</sup>



001-C-001: “There was a time when the idea of letting my mother go was unacceptable. (...). It took time, the path of palliative care was also fundamental in this, to learn to let her go and respect her wishes.”

TYPE Original Research

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001-C-007: “We felt so cared for by nurses and doctors who came to our home with an incredible cadence and interacted with us flawlessly.”

002-C-052: “So much relief, my husband had no pain and lived well. And even more, he was peaceful, with me by his side all the time (...). Of course, if he had been suffering I would not have made it.”

002-C-063: “To me they (EPC) represented everything; to see her calm and without pain

can't explain, but we were smiling. Each visit has always been filled with serenity, even when the situation worsened, and the disease progressed. Knowing that you are not alone and that you can count on someone who guarantees you control over your suffering and respect for your will is a lot. And maybe that's what helped me most in accepting the idea of death.”





## Gratitude among advanced cancer patients and their caregivers: The role of early palliative care

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## Perceptions of Hope Among Bereaved Caregivers Who Received Early Palliative Care: A Lexicographic Analysis

Sarah Bigi<sup>1,\*</sup>, Vittorio Ganfi<sup>2</sup>, Eleonora Borelli<sup>2</sup>, Leonardo Potenza<sup>2,3</sup>, Fabio Eliardo<sup>4</sup>, Claudia Mucciarini<sup>4</sup>, Luca Cottafavi<sup>4</sup>, Massimiliano Cruciani<sup>4</sup>, Oreofe Odejide<sup>7,†</sup>, Carlo Adolfo Porro<sup>5,6,†</sup>, Camilla Zimmermann<sup>8,9,†</sup>, Fabio Eliardo<sup>10,†</sup>, Mario Luppi<sup>2,3,\*</sup>, Elena Bandieri<sup>4,†</sup>

The Oncologist®

Symptom Management

Changes in cancer patients' and caregivers' disease perceptions while receiving early palliative care: a qualitative and analysis

ELEONORA BORELLI<sup>1,3</sup>, SARAH BIGI<sup>2</sup>, LEONARDO POTENZA<sup>2,3</sup>, SONIA ELIARDO<sup>4</sup>, FABRIZIO ARTIOLI<sup>5</sup>, CLAUDIA MUCCIARINI<sup>4</sup>, LUCA COTTAFAVI<sup>4</sup>, KATIA CAGOSI<sup>4</sup>, GIORGIA RAZZINI<sup>4</sup>, MASSIMILIANO CRUCIANI<sup>4</sup>, ALESSANDRA PIETRAMAGGIORI<sup>4</sup>, VALERIA FANTUZZI<sup>4</sup>, ILARIA BERNARDINI<sup>4</sup>, LAURA LOMBARDO<sup>4</sup>, UMBERTO FERRARI<sup>4</sup>, VITTORIO GANFI<sup>2</sup>, FAUSTA LUI<sup>7,†</sup>, OREOFE ODEJIDE<sup>7,†</sup>, CRISTINA CACCIARI<sup>5,6</sup>, CARLO ADOLFO PORRO<sup>5,6,†</sup>, CAMILLA ZIMMERMANN<sup>8,9,†</sup>, FABIO EFFICACE<sup>9,†</sup>, EDUARDO BRUERA<sup>10,†</sup>, MARIO LUPPI<sup>2,3,\*</sup>, ELENA BANDIERI<sup>4,†</sup>

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# CONCLUSIONS

STUDIES CONFIRM MAJOR RISK FACTORS FOR ADVERSE OUTCOMES OF CG CARE:

- Inappropriate management of pain
- Poor prognostic understanding
- Lack of preparation for death

*EPC may represent a promising offering to address the needs of CG and is now recommended as part of routine cancer care.*



- Randomized Controlled Trials
- Qualitative/Quantitative Studies: Real Life Setting
- **Stigma about Palliative Care**



# Palliative Care Is the Umbrella, Not the Rain— A Metaphor to Guide Conversations in Advanced Cancer

Camilla Zimmermann,  
MD, PhD

Figure. Illustrated Metaphor of Late vs Early Palliative Care

A Late palliative care referral



B Early palliative care referral



Engagement and **Education of Policymakers, Stakeholders and the Public**



**AVOID STIGMA ABOUT PALLIATIVE CARE WHICH SHOULD BE ROUTINE CARE, DURING THE WHOLE ILLNESS TRAJECTORY:**

...«referrals are made too late because of misperceptions that palliative care is end-of-life care and palliative care remains synonymous with end-of-life care due to late-referrals...»



Iniziativa editoriale che raccoglie in formato video le testimonianze di **CG di paz onco-ematologici seguiti in EPC**. Spunto di riflessione sul bisogno di non curare la malattia solo attraverso la scienza e la tecnica, ma di ricollocare al centro della cura la **COMUNICAZIONE medico-paziente**.

Open Life Project: Caregivers raccoglie in formato Video le interviste di dieci familiari di pazienti oncologici ed ematologici, seguiti in un innovativo modello assistenziale di integrazione precoce di Cure Palliative con le terapie "onco-ematologiche standard". Il Progetto, che approfondisce una più ampia Ricerca sui temi della Comunicazione medico-paziente, comprende una sezione di Contenuti Speciali (Video/Cartacea) con gli approfondimenti di alcuni tra i maggiori esperti nazionali ed internazionali su: Cure Palliative Precoci, Spiritualità, Comunicazione e Ricerca. Le testimonianze sull'esperienza di malattia permettono di riflettere sul senso dell'esistenza e sul bisogno di non curare la malattia solo attraverso la scienza e la tecnica, ma di ricollocare al centro della cura la comunicazione e l'alleanza medico-paziente.

**Editore ARTESTAMPA**



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Open Life Project Caregivers

**L'ATTENZIONE E LA GRAZIA**



Open Life Project Caregivers

# L'ATTENZIONE E LA GRAZIA

Esperienze di Comunicazione nelle Cure Palliative Precoci in Oncologia ed Ematologia

a cura di  
Elena Bandieri  
Mario Luppi  
Leonardo Potenza



“Chiunque **Soffre** cerca di **Comunicare la sua Sofferenza**; e solo così facendo, la diminuisce veramente.

Coloro che soffrono non hanno, in fondo, bisogno d'altro, che di uomini capaci di prestar loro **Attenzione**.

Ma la capacità di dare attenzione a chi soffre è cosa rarissima; quasi un miracolo.”

**L'ombra e la grazia- 1943 - Simone Weil**

:



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UNIMORE/AOU Modena, Italy

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Early Palliative Care Service for Hematologic  
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## **Prof. Eduardo Bruera**

Palliative Care & Rehabilitation Medicine, UT MD  
Anderson Cancer Center, Houston, TX, USA.

## **Dr. Eleonora Borelli**

Department of Medical and Surgical  
Sciences, UNIMORE, Modena, Italy

## **Prof. Fabio Efficace**

Chairman Working Party QoL. Italian Group for Adult  
Hematologic Diseases (GIMEMA), Data Center and Health  
Outcomes Research Unit, Rome, Italy.  
Northwestern University, Chicago, IL, USA

## **Prof. Sarah Bigi**

Department of Linguistic Sciences and Foreign Literatures, Catholic  
University of the Sacred Heart, Milan, Italy

## **Prof. Oreofe Odejide**

Department of Medical Oncology, Dana-Farber Cancer  
Institute, Boston, MA, USA.

## **Prof. Carlo A. Porro**

Department of Biomedical, Metabolic and Neural Sciences. Center  
for Neuroscience and Neurotechnology,  
Rector, University of Modena and Reggio Emilia, Modena, Italy

## **Prof. Camilla Zimmermann**

Princess Margaret Cancer Centre, University Health  
Network, University of Toronto, Toronto, Ontario, Canada

